

**INVESTIGATION OF THE PALLIATIVE
CARE NEEDS OF PATIENTS TERMINALLY ILL WITH
AIDS**

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MPHIL UCT 2005**

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ACKNOWLEDGEMENTS:

Dr E De Vries: Supervisor

Mrs M Bezuidenhout: Social worker, Settlers Hospital

Valerie Clarke: Honours student Rhodes University

Carey-Ann Moorcroft: Honours student Rhodes University

Dr John Bennett: Settlers Hospital Board

Mrs I Solomon: CEO Settlers Hospital

Sister Siwa and the record room staff at Settlers Hospital

DISCLAIMER:

This is an original piece of research. Any aid in terms of assistance or information has been acknowledged or referenced.

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ABBREVIATIONS/ACRONYMS

AIDS: Acquired Immune Deficiency Syndrome

ARVs: Antiretroviral Therapy

CEO: Chief Executive Officer

DHMT: District Health Management Team

DOTS: Directly Observed Therapy

D and V: Diarrhoea and Vomiting

DG: Disability Grant

HAART: Highly Active Antiretroviral Therapy

HIV: Human Immunodeficiency Virus

JB: John Bennett

MB: Marietje Bezuidenhout

RDP: Reconstruction and Development

SAMJ: South African Medical Journal

TB: Tuberculosis

TV: Television

UCT: University of Cape Town

RESEARCH PROJECT

INVESTIGATION OF THE PALLIATIVE CARE NEEDS OF PATIENTS TERMINALLY ILL WITH AIDS.

SUMMARY:

This research project is an investigation into the palliative care needs and the implementation of those needs in terminally ill patients in Settlers Hospital, Grahamstown. The needs have been assessed by means of a questionnaire administered to patients admitted to the wards for pre-terminal and terminal care. The patients were identified by the medical and nursing staff in the wards. The patients were asked to sign a consent form to say that they were willing to participate in the program. The consent form was read to them in their own language by one of the nurses as most of the patients are illiterate. Included in the consent was a proviso that refusal to participate would not compromise their future care.

As a result of the questionnaire, a better understanding of the medical, social, psychological, economic, family and spiritual needs of this group of patients has been

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obtained. The problems identified have been summarized, and an action plan identified and completed for each patient. The action plan was discussed among the members of the palliative care team, the ward staff and the doctor in charge of the patient. An attempt was made by the palliative care team to address the problems identified.

The investigation was done by a team, comprising a practicing clinician, two psychology honours students, a social worker and a retired academic (JB) appointed by the hospital board to oversee health care in the hospital.

At the end of the period of assessment, the results were reviewed by the team and presented to the Hospital Board and the District Health Management Team as part of a motivation to designate a ward for palliative care in the hospital which will be accessible to people from the entire district for assessment and treatment. This will interlink with the current programs for home based care for AIDS patients being run by the local hospice unit and the introduction of antiretroviral treatment at the hospital and the local clinics.

The limitations of the study are an absence of a formal quality of life assessment tool but many of the symptoms investigated are part of formal quality of life questionnaires.

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3. INTRODUCTION:

Terminally ill AIDS patients account for a large percentage of all the patients seen in state hospitals. They are often admitted in the last stages of the disease with multiple problems and are managed by doctors with very little experience in dealing with terminal illness. Attention is paid to the medical conditions, which are treatable, but very little attempt is made to address the problems of pain management, itching skin, physical discomfort, emotional and psychological distress.

In the city of Grahamstown, the only hospital is a state hospital, Settlers Hospital that caters for the whole population. Private patients have the option to go to Port Elizabeth to one of the private hospitals there but the state patients are seen initially at the local hospital and then transferred if there are special needs. Therefore all the terminally ill patients with HIV will come to the hospital unless they have a medical aid or are managed at home by the Hospice sisters. The hospital serves a population of 137,000 based on the 1999 census as published by the East Cape Department of Health. Unofficial figures from the Department of Economics at Rhodes University put the figures at closer to 180,000. The Hospital has 272 beds and normally has an occupancy rate of 60 to 70%. It is presumed that the AIDS pandemic has resulted in 10% of the population being HIV positive and as the number of patients presenting with stage 3 and 4 AIDS has increased, this has impacted on the hospital in terms of increased pressure on medical beds and increased deaths, severe stress on the nursing staff and strain on the economic, physical and human resources.

As a quality control measure adopted by the Settlers Hospital Board, for the last five years, the folders have been reviewed of a randomly selected sample of all the patients that have died in the hospital each month for the purpose of quality assurance of the medical care and to upgrade this care where necessary. In addition this has enabled the hospital administrators to have some idea of the impact that HIV/AIDS is having on the hospital and the community in general.

The findings are presented and discussed at a regular monthly meeting and a summary presented to the Hospital Board.

The medical and nursing care is closely scrutinized. Initially the medical and nursing care was suboptimal and discussion between the nursing and medical staff served to address these problems. The general care improved, but it was noticeable that the nursing notes would often list symptoms such as painful mouth, difficulty in swallowing or skin discomfort which were not included in the medical notes or addressed in the treatment plan. It seemed that the nursing staff who were going through the nursing process when interviewing the patients were uncovering symptoms that the patients did not mention to the doctors unless specific questions were asked. This was particularly evident among the AIDS patients who were often too weak, depressed or without hope to volunteer symptoms.. Attention was then paid in the meetings as to how to match symptoms with treatment, the beginning of addressing palliative care for these patients. At the same time the principle investigator registered to do the palliative care course at UCT and with this a new impetus to address palliative care began. At the same time the impact of

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palliative care measures was emerging in terms of patient satisfaction, addressing the nursing distress at having to watch people die in pain and discomfort and reducing the frustration on the part of the medical staff who felt there was nothing that they could do. Over the years the numbers of patients dying of AIDS in Settlers Hospital has increased.

In a six month period between Dec 2002 and May 2003, 153 patients died with 55 dying from AIDS, a total of 36% of all deaths. Over a similar period in 2004 and 2005, between December and May 139 patients died, 57% of them dying from AIDS. (Figure 1).

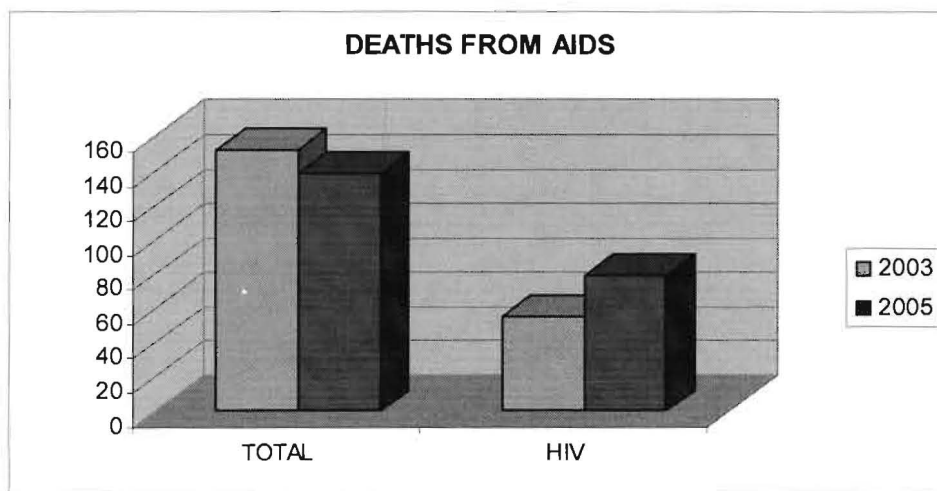


Figure 1: Increasing numbers of deaths from AIDS showing the changes in the absolute numbers of HIV patients increasing while the total deaths actually decreased.

In the period before the implementation of palliative care the average duration of life after admission among the patients dying of AIDS in 2002-2003 was 2 days.

From the beginning of 2004 an attempt has been made to institute palliative care in the

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medical wards and the role of palliative care in managing AIDS patients has been a focus in the monthly medical meetings. As a result of this program, the medical and nursing staff have become more aware of the needs of terminally ill patients. This has had an impact on the management of the patients.

In the period of time, April 2004 to January 2005 AIDS accounted for 155 of the 313 or 49.5% of the total number of deaths in the medical wards. Females accounted for 70% of these deaths. Of the total numbers of AIDS deaths, 83 patients were reviewed. Among these patients who all died of terminal AIDS, the average stay in the ward prior to death was 8 days (6 days among the males and 8.79 days among the females). The improvement in the duration of life was ascribed to the introduction of palliative care.

The patients had multiple medical problems but the commonest primary cause of death as noted on the death certificate was Tuberculosis (TB) in 46.9% of the patients, followed by diarrhoea and vomiting in 14% and meningitis in 14%. (Table 1). This pattern is similar to the pattern observed by Badri et al who looked at the incidence of AIDS-defining illnesses in Cape Town¹ and found that the commonest disease was tuberculosis among the HIV patients being followed up in their clinic.

Tuberculosis is in general well treated in the area., There is a TB hospital and several clinics. There is also a dedicated TB doctor serving the clinics in apart time capacity. Directly Observed Treatment (DOTS) is implemented through the local clinics and the staff are well aware of the management of TB and have regular contact with the local doctor managing the clinics and the TB hospital. The AIDS related TB deaths are due to

the patients arriving with far advanced disease at the hospital, the difficulties associated with making the diagnosis of atypical TB and the generally poor condition of the patients.

TABLE 1: CAUSES OF DEATH IN TERMINAL AIDS PATIENTS

DIAGNOSIS	NUMBER	PERCENTAGE
TB	39	47
GASTRO-ENTERITIS	12	14.4
MENINGITIS	12	14.4
PNEUMONIA	9	11
RENAL FAILURE	2	2.4
CENTRAL NERVOUS SYSTEM	2	2.4
GASTROINTESTINAL TRACT BLEED	2	2.4
SKIN INFECTION/SEPTICAEMIA	2	2.4
GENERALISED HERPES ZOSTER	2	2.4
KAPOSI'S SARCOMA	1	1

The medical care of the patients was generally good but symptom control particularly with regard to pain management tended to be poor. Reviewing the folders in 2004 and 2005 between November and March revealed that symptom control at the end of life with treatment for pain, nausea and vomiting, diarrhoea or other symptoms was

implemented in 43% of the AIDS patients and 22.5% of the non AIDS patients. The implementation tended to fluctuate during the year as the medical staff changed. The medical ward is staffed by doctors doing their community health service who tend to be fairly inexperienced and do not seem to have been exposed to palliative care training during their undergraduate training and permanently appointed medical officers who have often graduated many years ago and also have not been exposed to any palliative care training. These medical officers rotate through the wards.

For the last two years, palliative care has been one of the foci of the medical meetings and one of the interests of the team involved in the roll out of anti-retroviral treatment. As the new doctors are exposed to this approach they tend to start addressing the issue of symptom control. Palliative care for the terminally ill patients as evidenced by attention to symptom control when assessed month by month, showed a tendency to improve. However when the rotation of staff or the end of the year served by the community health doctors, placed new staff in the medical ward during January and February, the attention to palliative care fell off initially and then gradually started to improve again with time and ongoing training.(Figure 2)

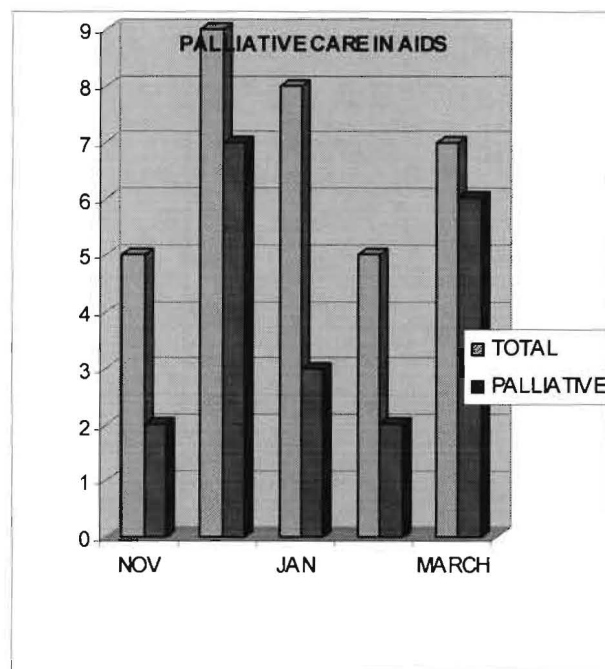


Figure 2: Palliative care in terminally ill AIDS patients showing the total number of AIDS patients in the ward in the ward (column 1) and the number of these patients receiving palliative care (column 2). As the medical staff became more aware of the role of palliative care the number of patients receiving this care improved. With the change of staff at the end of the year the numbers fell off and then improved again.

The implementation of palliative care fluctuated in the wards as staff changes but over a 5 month period only 59% of the patients received any form of palliative care. Among those receiving palliative care the duration of life was significantly extended. The average duration of life was now 8 days compared to 2 days as in 2003 as noted at the beginning of the study.

Despite the fact that the patients were not getting adequate symptom control, the costs of managing their terminal illnesses were enormous with most patients having full medical care including expensive intravenous and oral drugs, extensive blood tests, Xrays and full nutritional support. Total medical care was continued right to the end of life with no recognition that palliative care rather than full curative care would have been appropriate. Very little attempt was made to address the patient centered needs of the terminally ill and to improve quality of life rather than duration of life.

It seemed important to change the approach of the medical team to a patient centered approach and to assess the needs of the patients as they perceived them. In order to do this, it was necessary to give the staff some idea of the scope of the needs of these patients and to document these findings in the proposed research.

An initial review, pilot study, of the needs of these patients was carried out last year in 2004 between October and November 2004 as part of the ongoing quality control of patient care. The review was done on 25 terminally ill HIV patients in the wards. There were 12 males and 13 females. The average age of the patients was 32 years. Each patient was assessed by means of a questionnaire administered by a member of the palliative care team. This questionnaire was based on one used to assess the needs and response to pain management among rheumatoid arthritis patients. The research done on pain management was presented to the South African Rheumatology Association conference in 2001². The patients investigated in this study were very similar to the patients investigated in the current study on AIDS patients in that they were also

hospital patients living in the city and environs of Grahamstown, generally unemployed and in socio-economic group four or five, mainly xhosa speaking and in receipt of a state pension. The only difference was that they tended to be older than the current AIDS patients. They therefore broadly reflect the typical outpatient population of the hospital and therefore the community served by the hospital. The questionnaire was modified to address the needs of a group of AIDS patients in that more attention was paid to family and spiritual issues. The rheumatology questionnaire was in English and administered with a translator. This may lead to inconsistencies but it is the modus operandi for all treatment and management in the hospital and the staff are familiar with the process of communicating this way and all implementation of need would come as a result of this form of communication. It is an inescapable reality of medical treatment in South Africa.

This pilot study was undertaken at Settlers Hospital in October and November 2004. Overall it was found that the patients required medical care (80%), psychological care, addressing anxiety or depression (56%), social care, addressing financial or family issues (44%), family care to arrange support systems or child grants (40%), money (24%) and spiritual care (16%). Some of the patients required more than one category of care. The most troublesome medical symptoms in these patients were weakness (64%), pain, cough and fatigue (44% each), fever and loss of weight (32% each) and nausea and diarrhoea (20% each). (Figure 3). This results as recorded in figure 3 showed the number of patients complaining of each symptom (vertical axis) and the symptoms they experienced

(horizontal axis). These findings were used as the basis for a questionnaire to assess the needs of a larger group of patients.

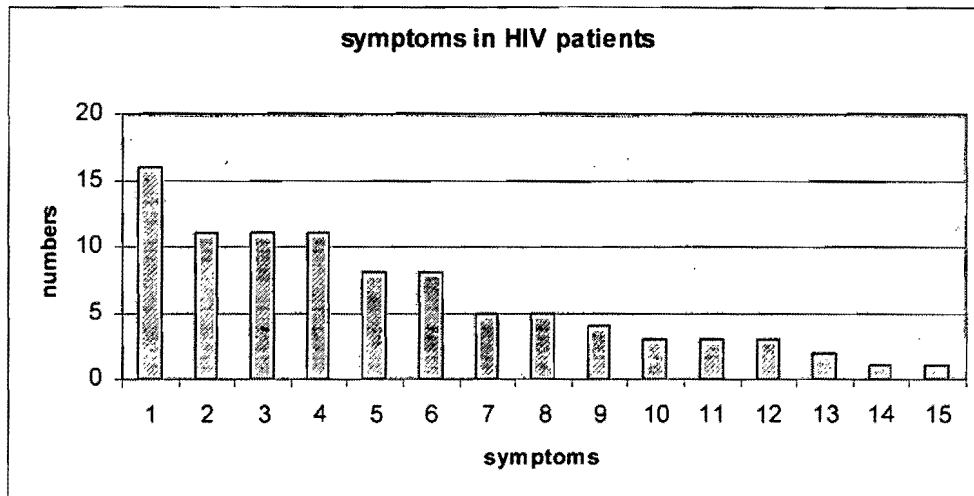


Figure 3: The medical symptoms experienced by terminally ill patients with AIDS

SYMPTOMS: 1. Weakness 2. Pain 3. Cough 4. Fatigue 5. Fever 6. Loss of Weight 7. Diarrhoea 8. Nausea 9. Skin 10. Headache 11. Itch 12. Eyes 13. Anorexia 14. Dyspnoea 15. Mouth

4. LITERATURE REVIEW:

There is an enormous amount written about treatment in AIDS patients. However, there is somewhat less interest in palliative and terminal care. Palliative care has commonly been regarded as only the care of patients who are in the terminal phases of disease but increasingly has been recognized as relevant for the management of patients from the

time of diagnosis. The introduction of HAART has tended to exacerbate the tendency to medicalise the problem. Selwyn³ notes that there is “a loss of perspective on chronic disease and the issues relevant to progressive, incurable disease and end of life care.” In addition there has been a tendency to under-treat symptoms such as pain, anorexia, loss of weight, fatigue, nausea and vomiting and dyspnoea. Once again Selwyn has commented on this issue when he points out that as AIDS evolves into a chronic illness, the palliative care needs are likely to increase⁴. Despite this there has been a tendency for the gap between the observed role of HIV treatment and palliative care to widen⁵. In addition, the fact that there is limited evidence to show that palliative care improves the outcome for patients with AIDS⁶ does not help to improve this perspective. However palliative care has been identified as an important component of HIV/AIDS services in the United States⁷ and can be seen as an integral part of the treatment program at all stages of the disease.

The services in Africa have lagged behind in the provision of active treatment for AIDS and also in the availability of palliative care. Dinat and Russell⁸ in their article on terminal and palliative care in adults, observe that relatively little work is being done in this field globally but particularly in Africa. They note that, “at the International AIDS Conference in Barcelona in 2002, of the 8719 abstracts accepted, only 53 were about palliative or home based care, 5 from Africa and none from South Africa.” In addition much of what has been written has come from the western world and is not directly applicable to Africa or South Africa.

The needs of patients in Africa may differ significantly from patients in the more developed world, because of the restrictions of poverty, a different approach to family relationships and the need to stay within the community rather than to die far away from home. Kikule in her review⁹ of what would constitute a good death in Uganda makes the point that in this population, "The home was the preferred site of care because it was cheaper, the patients felt safe and surrounded by family and there was privacy. A good death occurs at home, in the absence of pain and other distressing symptoms, without stigma or a sense of dependence, and with adequate finances for the basic needs".

Cecilia Sepulveda et al¹⁰ have shown that the whole issue of the needs of patients have to be reassessed to give population specific quality care at the end of life and that if this is done the suffering that accompanies death in Africa can be avoided or relieved.

In sub-Saharan Africa, the goal has been to provide home based care for terminal AIDS patients but despite the fact that this policy has been implemented widely, the providers report problems with pain control due to lack of availability of drugs, trained health care providers, stigma on the part of the community who were unhappy with the presence of these patients in their midst due to fear of the disease, and legal restrictions¹¹. In Uganda palliative care has been implemented using the Hospice organization but the delivery of services is severely constrained by lack of financial resources¹².

In South Africa where there is an enormous stigma against those patients dying with AIDS, many of the patients are rejected by their families and have no choice but to die in hospital. The sense of isolation and fear that results from being admitted to hospital may exacerbate the distress experienced by these patients. The attitudes of staff to patients

with AIDS and the apparent indifference to the suffering of such patients is often in contrast to what might be expected from dying within a loving family. In particular, the approach to palliative care in the formal health services is poor due to lack of training and the stigma associated with the diagnosis¹³. Harries has stated that for there to be any hope of reducing HIV incidence and curbing the morbidity and mortality the approach to care must change and include psychosocial support, screening for diseases, clinical care for opportunistic infections, palliative care and the possibility of antiretroviral drugs among other programmes¹⁴. However instituting palliative care may be unusually difficult because of issues such as patients' refusal to adhere to treatment or refusal to accept, acknowledge or plan for death¹⁵. This may in part be due to the fact that individuals living with AIDS experience uncertainty due to the unpredictability of death. They live with a chronic illness with episodic major illness alternating with periods of relative wellness¹⁶. In addition the clinician may experience great difficulty in deciding when the patient has entered the terminal phases.

Generally palliative care to AIDS patients is limited world wide and impeded by lack of recognition of the needs and a lack of support systems¹⁷. A study from Rome showed that opioid analgesics were used in less than a third of terminally AIDS patients despite the fact that almost 60% of the patients experienced pain¹⁸. This study also revealed that almost one third of the patients died alone without having family, their partner or a friend near. Apart from the isolation and stigma, symptom management is usually very poor in these patients. Among the symptoms common to the AIDS patients pain and the management of this pain has been shown to be particularly poorly managed¹⁹. This may

in part be due to the fact that “physicians think of pain as a symptom to observe and explore in diagnosing and monitoring disease rather than a complaint to relieve quickly or fully”²⁰. In South Africa Norval has identified the commonest symptoms in stage 4 AIDS patients as being pain (98%), weight loss (81%), loss of appetite (70.9%), low mood (69.9%), weakness (66%), dry skin (56.3%), diarrhoea (53.4%), nausea and vomiting (44.7%), cough (44.7%) and fatigue(42.7%)²¹. The conclusion she draws is that reforms are needed to increase knowledge and education in the palliative management of AIDS. The presence of pain results in a reduction in survival rate and a deterioration in activities of daily living²². The pain experienced may be somatic, visceral or neuropathic pain and may be managed with a range of treatments but generally current approaches need to be improved²³.

The AIDS pandemic has resulted in an enormous burden on the health care services but also on communities who have been required to cope with the dying patients and the families that are left behind. Palliative care has an important role to play in not only improving the medical care and symptom control of the patient but also in dealing with psychosocial issues such as the future care of the children, paying of school fees, identifying future child carers. In particular Kramer has identified among other issues, the importance of developing guidelines for the patients to write valid wills to ensure that the partners and children are provided for²⁴.

High quality AIDS care needs to incorporate all the aspects of good palliative care addressing physical, medical, spiritual and psychosocial components. Armes and Higginson have shown that high quality care includes “competent, skilled practitioners

(effectiveness); confidential, non-discriminatory, and culturally sensitive care (acceptability); collaborative and coordinated care (efficiency); flexible and responsive care (access and relevance to need); and fair access to all clients (equity)²⁵.

The rollout of the antiretroviral program has begun to impact on the previously noted response to AIDS noted among patients and the community at large. Dr Tony Moll has observed that ARVs are changing the stigma of AIDS and that communities are beginning to accept patients with the disease²⁶. However he also notes that there is a need for a step down form of medical care to support patients in the initial phases of treatment. He notes that these patients “would almost certainly otherwise expire in the overburdened and understaffed state hospital”. Step down care in this setting would include good palliative care to control symptoms and address psychosocial and spiritual issues that arise with the implementation of care requiring the need for a family supporter, an enormous pill burden, a lot of medical intervention and possible side effects from the treatment.

5. RESEARCH DESIGN AND METHODOLOGY:

The study was designed to investigate the needs of the patients. Needs could be identified as physical or medical needs which would include symptom control, food or drink and environmental issues, spiritual needs, psychosocial and financial needs or worries.

The assumption was; that these needs were currently unmet with conventional medical treatment, and that interviewing the patients would explore these needs and enable the

team to implement a program to address these needs. An additional assumption was that the current expensive medical model of managing the patients with excessive amounts of medical treatment was failing to address their needs and that a more patient focused management plan would both be more successful at improving the quality of care and possibly less expensive in that symptomatic treatment with oral medication is often cheaper than curative medicine which requires extensive investigation, intravenous treatment and monitoring which often increase the costs substantially. Haile noted in 2000 that there are very high inpatient costs to managing end-stage HIV disease and estimated that costs per patient were of the order of R45,000²⁷.

A pilot study was done in 2004 on 25 patients between August and November 2004 and as a result of this the questionnaire was modified so that it would be easier to use. This questionnaire was further modified in accordance with the requirements of the ethics committee at UCT. The data from the pilot study was not included in the current study because it had not received ethics approval.

The needs of in-patient terminally ill AIDS patients were collected over a four month period extending from February 2005 to May 2005. The data was collected by personal interviews with the patients conducted by one of the interviewers accompanied by a member of the nursing staff who acted as a translator and independent observer of the

process. The interviews were done to suit the convenience of the nursing staff primarily on a Monday or Thursday afternoon when the ward was relatively quiet. The program was part of an ongoing process on monitoring quality of care in the hospital. The

monitoring process takes the form of a monthly meeting between nursing, medical and other disciplines in the hospital. At this meeting, the problems in identifying and coping with the needs of patients with AIDS has been highlighted by the ward staff. The social worker has identified the fact that the nursing staff experience enormous stress in dealing with these patients. The staff were therefore involved in the need to address the management of care for these patients and regarded the program as beneficial in two respects. Firstly it meant that some active intervention to help the patients would result, and secondly that it would motivate the need for a palliative care ward. Two of the sisters in the ward have had palliative care training and were therefore very supportive of the process.

The staff members involved in the interviewing process are long standing staff members most of whom had been involved in the pilot project. They were all fluent in English and had administered the previous questionnaire and consent form. The initial consent form was translated into Xhosa.

The interviewing team comprised three psychology students, two of whom did the bulk of the work, VC and CM, and the principal investigator. The patients signed consent to be interviewed with the proviso that they were under no obligation to be interviewed and that they would suffer no deterioration in the quality of clinical care they received. The consent form did not state that the patients were terminal and they were not told that they were regarded as terminal but they were aware that they were very ill. It is difficult to assess whether patients with AIDS are terminal and not all the patients have

died. In some cases the intervention would have altered the outcome.

After an interview was completed the student discussed the issues raised in the interview with the principal investigator and on occasion with the social worker, MB, and conclusions were drawn as to what could be done to address these issues.

Recommendations were made to the social worker, the nursing staff and the medical staff as to changes in the care plan. If necessary the patients were referred to the local hospice organization for follow up.

The data collected was captured using a Microsoft Office Excel 2003 program. The numerical data was then analysed using graphs created by Excel. The qualitative data was captured from the questionnaires and grouped according to common themes.

5.1 AIMS:

The aims of the investigation were to investigate the needs of terminally ill patients with AIDS at Settlers Hospital in the Eastern Cape to obtain some insight into the problems faced by the patients, the medical and family carers to give some over-view as to how these might be managed.

5.2. OBJECTIVES:

The overall objectives of the study were to obtain specific information about the needs of terminally ill AIDS patients.

The specific objectives were to:

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- Design a questionnaire
- Identify terminally ill AIDS patients who would be representative of terminally ill AIDS patients in the community
- Administer the questionnaire to these patients to obtain a demographic profile of the patients paying attention to age, gender, socio-economic, educational profiles, interpersonal relationships and access to spiritual support and to identify their specific needs as perceived by the patients rather than the staff or the people involved in their care
- To attempt to address these needs and to then follow up the patients to get some idea of the outcome of the disease and whether some of the needs had been addressed
- To use this information to introduce palliative care principles to the hospital management of future terminally ill patients

The objectives were achieved using the following steps:

- The questionnaire was designed using a format previously used to identify the management of pain in patients with rheumatoid arthritis.
- The questionnaire was discussed by the palliative care team.
- The questionnaire was reviewed by the retired academic advisor JB and altered according to his suggestions.
- The questionnaire was then submitted for ethics approval to the University of Cape Town ethics committee

- It was then modified according to the advice of this committee
- The committee passed the modified questionnaire
- The palliative care team which comprised the social worker, Mrs Bezuidenhout, two Rhodes students and the principal investigator decided that the questionnaire would be administered to all available patients who were critically ill with AIDS and appeared to be terminal in the hospital on Monday afternoons and some Thursday afternoons, a time selected by the nursing staff as convenient for them, when this was possible, for a period of four months.
- The patients were identified by the doctors and nursing staff working in the wards.
- Having identified the needs, an attempt was made to address these needs
- An attempt was made to follow up all the patients to assess the outcomes.

The underlying hypothesis is that patients are dying in large numbers in our hospital despite good medical care. It seemed therefore that we were possibly unable to alter the outcome, or we were missing some key issues related to the disease which were influencing the outcome, or finally that we were not addressing issues related to psychosocial or spiritual needs which were influencing the outcome. In identifying the needs and attempting to address them it was hoped that we could either influence the outcome or at least identify the fact that in these very ill patients, the only option was palliative care. It was also possible that the only way that good palliative care could be achieved was by creating a palliative care unit dedicated to addressing the needs of these patients, which could offer the specialist intervention needed.

5.3. RESEARCH DESIGN:

This study is an empirical study, primarily quantitative and ethnographic in nature with *** some qualitative indices comprising text and numeric data. The data was collected by interviewing individual patients, in a one to one structured interview, a technique which provides in-depth insights into the problems among a specific community of patients. The limitations are the fact that the study design does not allow for rigorous measurement of the data and also that the findings may not be generalisable to a wider group of patients.

The design of the questionnaire and the range of questions was intended to give an overview of the impact of AIDS on the patient as an individual and at a family level and to give some indications of the socio-economic factors impacting on the patients which may influence the response to treatment. *** The questionnaire comprised mainly one word answers to allow for an overview of the problems. The patients were weak and not able to give extensive replies to very searching questions. However space and time was allocated for the patients to expand on their replies if they wished to do so. The interviewer was also able to add a comment if the patients exhibited any wish to expand on the topic. ***

5.4. THE RESEARCH METHOD:

The patients were selected from the patients admitted to the medical wards of Settlers Hospital. All patients in the ward on Mondays and Thursdays who were admitted with

stage 3 or 4 AIDS, as defined by the WHO²⁸ were eligible to be interviewed. Patients were not interviewed if they were assessed by the doctor in charge of the ward as being too confused or unable to communicate or if they did not wish to participate. The interviewer followed the set questions on the questionnaire and recorded the answers. The majority of patients (72%) were unable to speak English and the questions were translated by a nursing assistant, a nursing aide or a sister. The staff and the patients are accustomed to this method of communication which is the norm in the hospital where very few of the medical and paramedical staff are xhosa speaking.

At the end of the interview a summary of the particular problems was made and a management plan outlined. The plan was discussed with the patients and implemented.

The patients were followed up to see if the management plan addressed the problems identified.

The data was collected using a Microsoft Excel spread sheet and analysed in terms of demographic details, social and financial information, the family situation, medical symptoms and needs, and social and psycho-spiritual needs.

The time frames were four months for data collection and two months for analysis and writing up the material. At the end of the process the patients were followed up to investigate the outcome.

5.5. POTENTIAL SHORTCOMINGS OF THE RESEARCH

The greatest problem in the process is interviewer bias. In order to protect against this the interviews were carried out by a team and had a nurse who acted as a translator and observer. Another bias can be created by social desirability effects. In other words, the subject says what he thinks the interviewer wants him to say. This potential bias would particularly influence replies to questions about social interactions, family relationships and issues related to societal rejection where the patients would be inclined to offer the socially acceptable response.

***The value of having a member of the nursing staff involved in the process was that the staff member could indicate whether the comments made by the patients confirmed to the observations of the staff. In particular, the patients might say that the family were visiting and that relationships were good and the staff member was in a position to verify this claim. According to the staff, the claims made by the patients could be substantiated by their observations of family visits.

The nursing staff in the wards were able to independently confirm questions relating to whether the family and friends were visiting and whether the relationship between the patient and the family were good or not.

***Another limitation of the study is the fact that a questionnaire designed to encourage one word answers has limitations in gathering data related to qualitative research. The reason that this format was selected was that the patients are very weak and it is difficult

to justify using an extensive questionnaire in a study on terminally ill patients. The study combines quantitative data of patient numbers and symptoms with qualitative questions such as mood and emotional states. The data does have limitations in terms of qualitative research but this primarily a clinical study to improve management rather than a research tool and in this context gives access to sufficient information to be useful.

5.6. ETHICS:

Any research process requires consideration of the ethics of the process to ensure that the research process is conducted in an ethical manner. This is particularly important when research is conducted on terminally ill patients who are particularly vulnerable. This research project has been assessed and passed by the ethics committee at UCT. The interviews were done in the presence of a member of the nursing staff of the ward. This might increase the duration of the interview but the interview was conducted in a relaxed unpressurised manner. Sometimes family members were present if they were visiting at the time of the interview. The implementation of palliative care recommendations were at the discretion of the doctor in charge of the ward who was not a member of the palliative care team. In this way it was felt that the patients would be ensured of good quality care with no ill effects resulting from the program. The patients signed a consent form and were assured that not participating would not affect the quality of care they received. (appendix 1).

6. RESULTS:

A total of 50 patients were interviewed. A further 5 patients were approached for an interview and could not be interviewed because three were too ill and two refused to be interviewed.

These patients reflected the profile of patients in the hospital at the time when the interviews were done. There are 44 beds in the medical ward and normally 16 beds would be occupied by males and 28 by females. This ratio is very similar to the ratio of male and female patients with AIDS. The majority of patients are Xhosa speaking and at any time approximately one third of the patients are admitted because they have severe symptoms due to AIDS and are considered to be potentially terminally ill..

The interviewing team allocated time for the research in accordance with the request by the nursing staff to come at a relatively quiet time. All of the patients were known to be HIV positive and they were all stage 3 or 4 according to the WHO classification²⁹.

This staging would imply that the patients were entering the terminal phases of the disease if they remained untreated. The fact that they had been admitted implied that they were critically ill. There is an enormous pressure on beds in the hospital and the patients are only admitted if they can no longer be treated by the hospital HIV clinic, the local clinics or the Hospice staff at home.

DEMOGRAPHY:

AGE AND SEX DISTRIBUTION:

The distribution of the patients by sex showed that 70% of the patients were female, a pattern observed generally in Africa where the main mode of transmission is by heterosexual penetrative intercourse³⁰ (Figure 4). Very few of the women were married and only three were living with their husbands.

The average age of the patients was 36 years and broken down according to sex was 37.6 in the males and 35.2 in the females. This is somewhat older than the age distribution of the patients diagnosed as HIV positive, reflecting the time that it takes for the disease to progress to stage 3 and 4. Surprisingly the age of the males and females was very similar as most studies have shown that women tend to acquire the disease at a younger age.

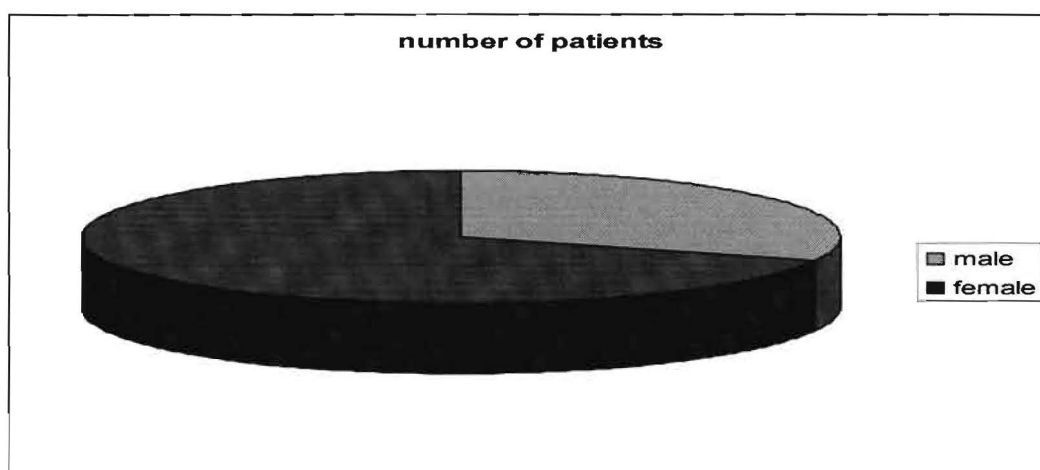


Figure 4: Sex distribution of patients interviewed

RURAL AND URBAN ORIGIN:

Grahamstown is situated more than 100 kms from a major centre, Port Elizabeth, and the only hospital is Settlers Hospital which is a level 1 district hospital which implies that all the patients live in a rural setting. However a distinction could be made between those patients who live on farms and those who live in the town. 32% of the patients came from a rural background and 68% from the town. (Figure 5).

The urban dwellers often had access to Reconstruction and Development (RDP) housing with running water and electricity. In total 52% of the patients lived in brick houses, 26% in mud houses, 14% in cement houses, 6% in corrugated iron houses and only 1 lived in a shack. Of the 16 patients who lived in a rural setting 44% lived in brick houses, 38% in mud houses and the remainder in cement houses. Overall 72% had access to electricity and 52% had running water in the houses.

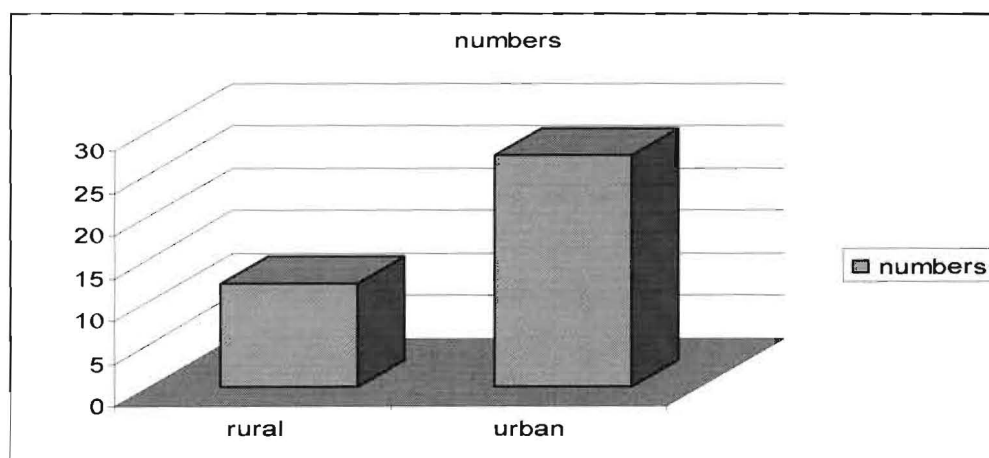


Figure 5: Geographical background. Urban Dwellers live in the town and rural dwellers live on the surrounding farms.

TRANSPORT:

Only two patients had their own transport. The remainder relied on public transport which is erratic and very limited or “taxi’s” which are expensive. Currently the daily rate for a domestic worker to get to work from the township and return home in Grahamstown is R8.50. The pensions are R750 a month and the cost of daily or weekly transport would take up a significant percentage of the total family income. This cost would be the same as the cost of getting to the hospital and has implications for ongoing care and attending clinics for antiretroviral treatment which would require at least a monthly visit.

SOCIO-ECONOMIC FACTORS:

Only 12% of the patients were employed. This reflects in part, the fact that they were too sick to work by the time that they were admitted to hospital and in part the poor socio-economic conditions of the area. Of the unemployed patients, 57% had stopped working but 43% had never worked. Only one patient was still at school. (Figure 6).

The unemployment rate in the area is approximately 80% and patients who are unwell have almost no chance of finding any kind of employment. A large number of the people in the area depend on social grants or pensions to survive.

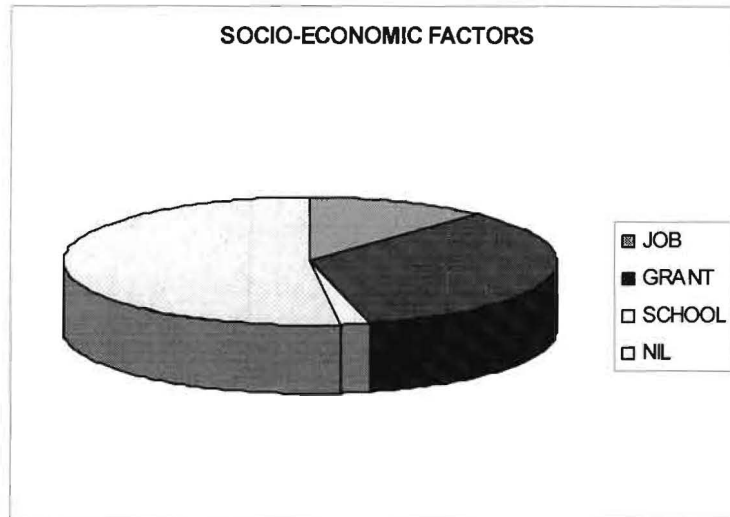


Figure 6: Employment and economic data to show source of income.

EDUCATION:

Apart from the poor socio-economic conditions and the lack of employment opportunities, lack of education contributes in part to the lack of employment. Only 10% of the patients had passed matric, 10% had reached matric but failed, 46% reached senior school, 32% reached only primary school and 1 patient had no education. (Figure 7).

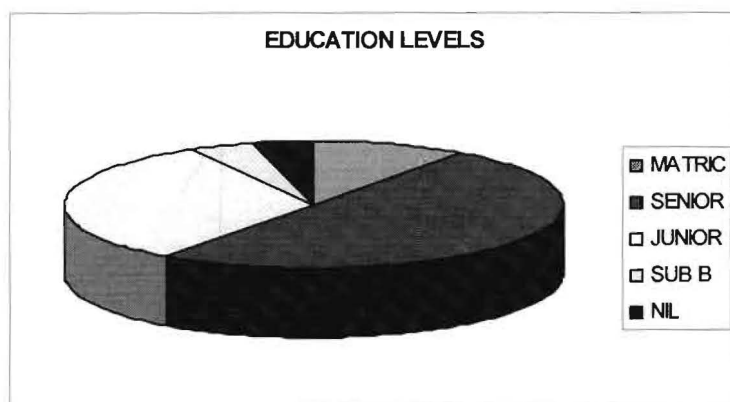


Figure 7: Education levels among the patients

SOCIAL GRANTS:

Of the unemployed patients, only 36% had grants. A personal communication with the social worker revealed that, obtaining a grant requires making an appointment to see the doctor who signs the forms and then waiting for about 6 months for the grant to come through. This is difficult for very ill patients who do not have the strength to get to town to go to the office or to stand and wait. In addition many of the grants have been summarily stopped and have to be reapplied for requiring more waiting.

A major impact on the socio-economic effects of the disease is the cost of funerals particularly if there are several within one family. Only 46% of the patients had a funeral policy to cover the cost of their funerals. Factors militating against having a funeral policy were mainly economic due to the cost of the policies and lack of future planning.

In a similar vein, only 22% of the patients had made a will.

DEPENDENT CHILDREN:

There were a total of 65 children dependent on the patients interviewed and none of the patients had made any provision for the future economic support of these children beyond applying for a child grant from the state.

A response to questions about the need for social support revealed that 72% of patients felt the need for some form of social intervention, particularly help with grants and children.

PSYCHO-SPIRITUAL FACTORS:

It has been frequently noted that isolation and rejection are experienced by the patients with AIDS. However, this did not seem to be a major problem in this group of patients.

The question exploring whether the patients regularly attended a church or had close links with a church community revealed that 82% actively participated in church activities and even when they became too ill to go to church, members of the church or the minister would still continue to visit them. 90% of the patients had close ties with the family and regularly received family visitors although few had friends who visited them.

The response as to whether the family was aware of the diagnosis was almost uniformly positive if the family was regularly visiting them.

These unexpected responses could have been related to denial of problems within the family but there was independent corroboration from the nursing interpreter who confirmed that the family did visit them.

In addition, Grahamstown is a small community and the churches have become very active in supporting the patients with AIDS.

Responses to questions asked to assess the patient's mood were quite difficult to interpret. Generally the patients seem to have trouble with the concept of depression.

They could relate to sad or unhappy but this seemed to indicate a short term mood of the moment rather than a long term overall response to the situation. Only 34 % of the patients when asked about mood said that they felt sad depressed or unhappy, while 42%

said that they felt anxious or worried. The remainder claimed to be happy or to have a normal mood. However, when asked specifically about anxiety, 86% said that they were anxious about the future, their families or money. In addition, in response to questions about the need for psychological support, 36% indicated a need for counseling, visits from hospice or someone to help with issues in the family.

MEDICAL FACTORS:

The patients were all suffering from stage 3 or 4 AIDS and therefore were sick and it was to be expected that they would perceive medical and physical problems to dominate their perceived needs. Only two of the patients were on antiretroviral therapy at the beginning of the study. In 94% of the patients medical problems needed to be addressed. They were receiving optimal medical care within the limitations imposed by being in a small peripheral hospital, so that the medical problems were unresolved physical symptoms despite the medical care being given. Common symptoms were pain, loss of weight, weakness and cough. (Table 2). In general the use of simple remedies such as aspirin, and paracetamol were often not included in the treatment plan and the use of opioids was very uncommon. As the program continued this pattern started to change as the benefits of this form of treatment were perceived.

In addition to addressing symptoms the issue of referring the patients for anti-retroviral treatment was assessed and where possible the workup for this treatment was commenced.

TABLE 2: UNRESOLVED SYMPTOMS IN PATIENTS INTERVIEWED

SYMPTOMS	NO OF PATIENTS	PERCENTAGE
LOSS OF WEIGHT	32	64
PAIN	30	60
COUGH	29	58
WEAKNESS	26	52
FATIGUE	24	48
FEVER	18	36
VOMITING	13	26
ITCH	11	22
SKIN INFECTION	11	22
NAUSEA	9	18
ANOREXIA	9	18
DIARRHOEA	5	10
DYSPNOEA	5	10
DIZZY	5	10
VISUAL IMPAIRMENT	4	8
PERIPHERAL NEUROPATHY	3	6
DYSPEPSIA	2	4
INSOMNIA	2	4
RESTLESS	1	2
CONFUSED	1	2

The mortality rate among these hospitalised patients was 32% (16 patients died) during the study period confirming that they were terminally ill. The remaining patients were either referred for TB therapy, or referred to Hospice or the local clinics to start the ARV workup. Not all the patients had CD4 counts done. This was partly because they were too ill at the time of hospitalization for anti-retroviral treatment to be an option. Only 29 of the patients had had a CD4 count done and the average count was 101. The remaining 21

patients did not have a CD4 count but 10 of these died indicating that they were considered too ill to have a CD4 count as performing this test would indicate an intention to treat with anti-retroviral drugs. In general terms CD4 counts are done only as part of the antiretroviral program. A total of 6 patients who died had a CD4 count measured and the average CD4 count among these patients was 80. The average CD4 count among the patients who survived was 106 indicating that at this stage- a CD4 count was not a particularly good indicator as to who would survive long enough to get anti-retroviral treatment.

Only 2 patients were on antiretroviral treatment on admission.

The effect of the palliative care intervention in the patients who died was the use of medication to relieve suffering and to allow them to die more comfortably. The need for treatment depended on the symptoms that the patients were complaining of and the treatment they were already receiving. Additional treatment was designed to be add-on therapy, complimenting the treatment already prescribed. There was some resistance on the part of some of the doctors running the ward to the introduction of palliative care and sometimes there were problems getting the medication administered. The perception that Morphine is a dangerous and addictive drug persists among medical personnel and patients.

The forms of treatment needed for symptom control were usually fairly simple, including morphine, mouth care, metoclopramide, dexamethasone, amitriptyline or haloperidol.

The forms of treatment required in the patients who died were as outlined in Table 3 and

were similar to the interventions needed in the patients who survived. Of note is the fact that these interventions, in addition to being simple were also not expensive, indicating that improvement in care could be obtained without a major increase in cost.

TABLE 3: SYMPTOMS AND TREATMENT IN DYING AIDS PATIENTS.

PATIENT NO	SYMPTOMS	TREATMENT
1	DIARRHOEA	MORPHINE PANCREATIC ENZYMES
3	DEHYDRATED WEAK PAINFUL MOUTH	IVFLUIDS MORPHINE AMPHOTERICIN LOZENGES
5	DEPRESSION FATIGUE	NIL ADDED
7	WEAK, D AND V DYSPOEA	MORPHINE THEOPHYLLIN METACLOPRAMIDE
8	PAIN CONFUSED DEHYDRATED	MORPHINE(NOT GIVEN) IV FLUIDS
11	TEARFUL	AMITRYPTILENE
13	PAIN	MORPHINE
16	WEAK, DYSPOEA, WORRIED ABOUT FAMILY	IVFLUIDS, MORPHINE, HOSPICE
22	WEAK, ORAL	ON APPROPRIATE

	THRUSH, WORRIED ABOUT DG	TREATMENT HOSPICE
37	WEAKNESS WORRIED ABOUT FAMILY	HOSPICE
38	D AND V, CONFUSED, WORRIED	MORPHINE HOSPICE
39	THRUSH, WEAK, DYSPHAGIA	AMPHOTERICIN LOZENGES
45	HEADACHE, ALONE, NO FAMILY	MORPHINE, DECAMETHASONE HOSPICE
48	NAUSEA, ITCHY FEET, PAIN	HALOPERIDOL, MORPHINE, OMEPRazole, WHITFIELDS
50	DYSPNOEA, PAIN, WEAK	MORPHINE, AMITRYPTILENE

DISCUSSION OF THE RESULTS:

The majority of the women were single mothers with children living in a house with the grandparents or other more distant family members. This has implications in terms of the social consequences of the pandemic. If a single parent dies the children have no social support system other than the grandparents or family members they are staying with while the mother is sick. In a community where there is 80% unemployment and social grants and pensions are the only source of income, the burden of extra children is

enormous and the chance of those children receiving adequate care, education and social support to break out of the cycle of poverty is slender.

The distinction between rural and urban backgrounds has implications in terms of housing and access to treatment. The urban dwellers are increasingly being housed in RDP houses with running water and electricity. Access to electricity and water has implications in terms of home based care and the management of illness at home. They also have access to the clinics where the anti-retroviral program is being rolled out. The farm workers by contrast might have inferior housing and greater distances to travel to reach the clinics but they often have more support from the farmers who will help them get medical treatment and allow them to stay on the farm when they become ill.

The majority of the patients had very little education. The significance of poor education standards is reflected in the lack of economic opportunities but also in the difficulties associated with education about the risks of HIV and modes of transmission. The cultural norms of behavior patterns are difficult to change where communication opportunities are limited. A recent article in the South African Medical Journal (SAMJ) by Puoane and Hughes has highlighted the difficulties of countering cultural norms in implementing preventive disease programmes³¹. The absence of access to any information in the press, educational pamphlets and posters makes communities very vulnerable to disinformation campaigns about the dangers of would tend to further isolate people and reinforce cultural behaviour patterns. It also limits access to accurate information about anti-retroviral therapies and the role of vitamins in the treatment. These factors will also

have implications for the success of any anti-retroviral treatment program.

The absence of a grant impacts on the possible future treatment with anti-retrovirals because of lack of food and money for transport and also affects the children being cared for in the house.

The effect of the palliative care intervention on the symptoms that were not addressed was to improve these symptoms. In the patients who died the use of add on medication was to make them more comfortable and to relieve stress on the nurses and the families. In the patients who survived, the medication made them stronger and more able to cope with the curative medication they were receiving.

The medications given depended on the symptoms that the patients were complaining of and the treatment they were already receiving. Additional treatment was designed to be add-on therapy, complimenting the treatment already prescribed. There was no attempt to alter the medication prescribed by the doctor running the ward. There was some resistance on the part of some of the doctors running the ward to the introduction of some forms of palliative care and sometimes there were problems getting the medication administered. The biggest problem was in the use of morphine. The perception that Morphine is a dangerous and addictive drug persists among medical personnel and patients.

There were less psycho-spiritual problems than anticipated. This may have been because AIDS is now perceived as a treatable disease. Alternatively it is possible that the requirement to disclose ones status prior to receiving anti-retroviral treatment has led to a

greater level of awareness in the community.

OUTCOME:

The patients were interviewed while they were inpatients in the ward apart from 4 who were interviewed at Hospice just prior to admission. Following the interviews, the patients had medical treatment added, they were referred to the social worker to get help with the grants or referred to Hospice for ongoing care.. At the end of the process the patients were followed up to investigate the outcome of the intervention. The follow-up was done by means of reviewing the folders, contacting the local Hospice sisters or contacting the patient directly.

At follow-up, in the two weeks following the completion of the interviews, it was found that of the 50 patients, 16 had died (32%), 10 were still being followed up by Hospice (20%) for medical and psycho-spiritual support and with the possible aim of trying to get them on to antiretroviral treatment, 7 were either on ARVs at the time of assessment or were referred to start treatment and are now on treatment (14%), 6 were referred to the local TB hospital, Temba, for inpatient treatment (12%), 6 were referred to the clinics for follow-up and possible ARV treatment (12%) 4 were discharged home (8%) and 1 has been frequently readmitted to Settlers Hospital for ongoing anaemia (2%). (Figure 8).

Although these patients were assessed by the medical staff as being preterminal or terminal, only 32% had died by the end of the study which is very different from the situation with cancer patients. This may have been because of the palliative care input.

Alternatively the patients were not as sick as they appeared. But the results highlight one of the major problems in dealing with stage 3 and 4 AIDS patients. It is very difficult to decide when these patients are terminal despite the presence of severe symptoms, loss of weight and opportunistic infections. In addition, it is possible that the approach of therapeutic nihilism among the staff dealing with the patients may also have a severely negative impact on the outcome. When the staff are actively engaged in palliative care they are trying harder to address problems and this may improve the curative medicine implemented.

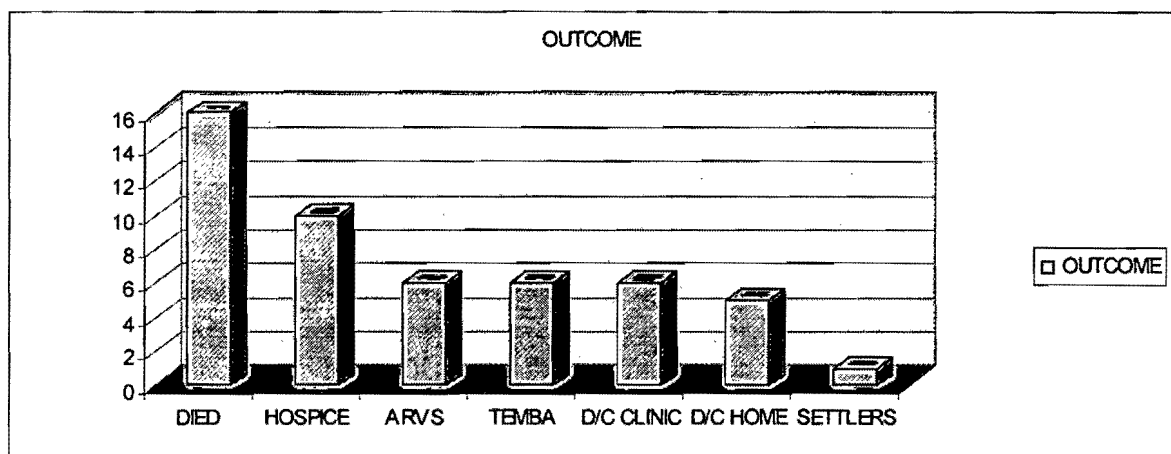


Figure 8: Outcome of palliative care intervention among the patients interviewed during the research project.

Following the palliative care intervention, an assessment was made to see whether the impact of the palliative care intervention had influenced the treatment of the patients in the ward. In line with the usual program of assessing the standard of medical care for the purposes of quality control, the patients who died in the month of May were assessed.

Among the patients with terminal AIDS, 73 % received palliative care and survived on average 8 days. Among the patients who died of other causes, 40% received palliative care and survived on average 8.3 days. This compared favorably with the figures of 2003 when none of the patients received palliative care and 2004 when 43% of the AIDS patients received palliative care. The program had impacted positively on the provision of palliative care in the ward.

Among these patients, 15 did not receive palliative care, 4 with AIDS and 11 without AIDS. The duration of survival among the AIDS patients who did not receive palliative care was 5.5 days and similarly the survival was 4.5 days among the non AIDS patients not receiving palliative care.

STUDENT RESPONSE TO THE PROGRAM

The two students who were most involved in the program were invited to comment and to have an interview with the social worker MB about their experiences. This was partly to get input from them about the program and partly to correct and reverse any adverse feeling about the program and their experiences dealing with terminally ill patients. They each filled in a questionnaire asking if they enjoyed being involved with the project, found it a challenge, interesting and educational and would do this again, whether they found it stressful, whether they could empathize with the patients, or felt disconnected from them and whether they felt upset dealing with the patients.

Both students responded positively. They enjoyed participating in the program and would do it again, they empathized with the patients but felt sometimes disconnected, unable to

relate to the patients and sometimes distressed but overall the experience was positive.

In the interviews student CM said that she had felt disconnected from the patients because of the social and cultural gap and became distressed at times. However she realized that she had grown a lot emotionally and found it an awakening life experience. As a result of her involvement in the project, she has gone on to do a Hospice Caregivers course. The second student VC enjoyed talking to the patients, it broadened her view on life and she felt she had grown a lot and she has also gone on to do a Hospice Caregivers course. The full interviews are appended. (Appendix 2)

CONCLUSIONS:

The study highlights many of the problems faced by patients with the onset of full blown AIDS. Terminally ill patients with HIV and AIDS account for an ever increasing burden of patients on the health care system. The cost of inappropriate treatments which are not directed at symptom control and which do not change the outcome in terms of reducing mortality is increasing and little attention is being paid to patient-centered care.

Investigating the needs of these patients identified specific gaps in the management which led to increased suffering. When palliative care was implemented the management of the patients improved and this may have contributed to the increased life expectancy.

The study also shows that the implementation of palliative care principles in the management of these patients is appropriate without increasing the costs and in the long term will result in better outcomes either in terms of a better quality of death or possibly a longer duration of life. It also seems to help to reduce the levels of stress among the staff

although this is a subjective opinion.

We have previously shown at the hospital in Grahamstown that good palliative care extends the duration of life among patients dying with AIDS from 2 to 8 days. (page 9).

In this study this work has clarified the problems as perceived by the patients and identified the ways in which they can be addressed. The needs to address both socio-economic and medical issues confirms that a multidisciplinary team is needed for the process.

An assessment of the palliative care needs among terminally ill AIDS patients demonstrated that the major needs among these patients were both medical and socio-economic. Responding to the needs improves the quality of care but may also reverse the therapeutic nihilism which seems to have developed in response to dealing with the AIDS pandemic.

Improving the quality of life for terminally ill required relatively simple and non expensive medication, referral to the social workers or to hospice and introducing the idea of anti-retroviral therapy.

The unexpectedly good survival rate of the patients may indicate that an improvement in medical care may result in an improved outcome in terms of survival time. In this study it is notable that 68 % of the patients followed up in the program survived for reasonable periods despite being regarded as terminally ill. The longer survival time allowed for better diagnosis and the initiation of appropriate treatment. 38% of the patients are

currently on antiretroviral treatment, TB treatment or have been referred to the clinic to be put on the program for antiretroviral treatment.

Generally the medical palliative treatment required was analgesics such as morphine, antipyretics such as aspirin or paracetamol, amitryptilene as a pain adjuvant, or haloperidol for restlessness or confusion. These interventions are generally cheap and will not increase the cost of the overall treatment of the patients.

The socio-economic conditions among the patients were poor. They were generally unable to work, had poor education and skills and only 36% received a grant. In addition almost no provision had been made for the future care of the children who would be left orphaned when they died, perpetuating the problem. Greater attention to socio-economic and family issues are important in managing AIDS patients. The aid of a social worker to help with the grants is invaluable. Food parcels can also be accessed from the dietician if the patients are referred. In addition referral to the local hospice unit to provide medical care and social support to the patients and their families is important for monitoring them and also providing access to antiretroviral therapy.

Palliative care interventions needed are primarily and initially for medical problems and then for socio-economic problems. Interventions will improve the quality of life of these patients but may well have an additional benefit in terms of prolonging their life expectancy long enough to allow for the intervention of antiretroviral treatment.

It is extremely difficult to predict which patients admitted to hospital with stage three or

four AIDS will die and therefore it is important to assess carefully each patient for good symptom control. Symptom control will improve the quality of life without increasing the cost of treatment significantly and allow for more active intervention with anti-TB or anti-retroviral treatment.

As the patients are offered anti-retroviral treatment they will live longer and need more medical intervention particularly in the first few months after starting antiretroviral treatment and this will primarily be symptom control using palliative care principles. Socio-economic factors such as grants for food, transport and family support will be critical to the success of the roll out of the anti-retroviral program.

This research project has demonstrated that palliative care is needed in a hospital handling terminally ill HIV patients to help control symptoms and meet psychosocial needs. In addition it has shown that the institution of palliative care may significantly improve the course of disease among these patients at very little extra cost.

In addition good palliative care is likely to significantly improve the success of any program focused on treatment with anti-retroviral drugs by reducing hospital deaths, improving the response to treatment, improving family and child care and improving and should be implemented with the roll-out of anti-retroviral treatment.

Further issues that emerged as being important and that need to be followed up include the effect of AIDS on the future of the children of these patients, how the issues of transport and how the difficulties with accessing grants can be resolved. Another issue

which was not addressed but which seemed to be important was the effect of the AIDS pandemic on the staff.

The complexities of dealing with the range of problems, the need for time to talk to the patients and the need for a multidisciplinary team would be best served by having a separate ward for these patients. The fact that the patients and staff found the program beneficial has been established and the next step is to set up the palliative care ward.

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University of Cape Town

8. APPENDIX 1:

PALLIATIVE CARE QUESTIONNAIRE

SETTLERS HOSPITAL, GRAHAMSTOWN

The aim of this questionnaire is to enable a multidisciplinary palliative care team working in the hospital to become aware of the needs of terminally ill patients, to assess these needs and to establish a service in the hospital that will address these needs. This questionnaire is confidential and will be seen only by the members of the palliative care team.

The data collection will include:

- Patient's profile
- Circumstances
- Emotional state
- Social support
- Medical history and management
- Planning

This program will focus on adult patients admitted to Settlers' hospital, Grahamstown, residing in the Makana and Ndlambe municipal and surrounding rural areas.

I consent to participate in a study to investigate the needs of adult AIDS patients in the hospital. The study will be done by means of a questionnaire administered to the patient to find out their opinion about the treatment and unfilled needs. As far as possible an

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attempt will be made to fulfill these needs.

My participation is voluntary and I understand that if I do not wish to participate this will not influence the quality of clinical management and care received by me.

The information obtained will be used in a study to investigate the overall needs of these patients to establish how these needs will be met and as a guide for the establishment of a palliative care ward.

Confidentiality of any information relating to any specific patient is guaranteed.

SIGNED:

WITNESS:

1. PATIENT'S PROFILE:

Name:

Address:

Date of Birth:

Birthplace:

Cultural background(tick where applicable): Rural: Urban:

Race:

Age:

Sex:

Religion:

Active member of church: Yes: No:

Has the minister of your church visited you in hospital: Yes: No:

Level of education:

2. FINANCIAL INFORMATION:

Employment history: Are you presently employed:

Length of time: Level of employment:

Do you receive a grant:

Are you worried about money: Yes: No:

Do you belong to a funeral plan:

If yes, what is the name: Monthly premium:

If no who will pay for your funeral:

Do you have any debts/loans and where:

Money (policy) left for your children/ family: Yes: No:

Do you have a will: Yes: No:

3. SOCIAL CIRCUMSTANCES:

Material structure of house: Brick: Mud: Corrugated iron

Size of house:

Number of rooms:

Is the house situated in a municipal or rural area:

Sharing the house with other people:

If yes with whom:

Do you own a fridge:

Running water in the house:

Sewerage in the house

Electricity in the house:

Do you have: Radio: TV:

Do you own a vehicle or do you use public transport:

4: FAMILY CIRCUMSTANCES:

Number of children (sex, age, who is caring for them at the moment and state of health of the children):

Are you worried about your family:

Have your family been visiting you in hospital:

Do you have a close relationship with your family:

Do your family know you are here:

Does your family know what is wrong with you:

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What is your relationship with your family;

Very close:

Good:

Bad:

No family:

5. EMOTIONAL STATE:

Do you feel (tick where applicable): sad; angry; worried; unhappy;
scared

What is your main problem at the moment:

What have you done to solve your problem:

Do you want to talk about it: Yes: No:

Do you (tick where applicable): cry often, find it difficult to sleep,
sleep too much, feel tired all the time, have no interest in life, other

Do you need to see a counselor in the ward or would you want to
be referred to Hospice

6. SOCIAL SUPPORT

How would you like to be helped:

Does anyone need to talk to your family about your illness:

Do you want someone to talk to your family about your illness:

Is your family visiting:

What worries you/what do you need:

Do your friends visit you in hospital:

7. INTERVIEWER'S OVERALL ASSESSMENT:

(Overall assessment of patient's emotional state):

9. MEDICAL HISTORY AND SYMPTOMS:

a. Presenting symptoms on arrival at hospital(tick where applicable)

Pain fever diarrhoea itch cough loss of weight weakness nausea

Fatigue skin problem anorexia visual loss vomiting other

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b Current symptoms (see above list)

c Since when is the diagnosis known to you:

Today under one month ago 1 to 6 months 6 months to one

Year other

d How did you find out

e What treatment have you been receiving:

f What are you worried about:

Pain family issues Any other symptoms Money Fear

Death Other

8. WHAT CAN WE DO TO HELP YOU (tick where applicable)

Contact the family/friends/minister of your church

Contact Hospice

Contact Social Worker

9. FIELD WORKERS ASSESSMENT:

66.

10.PATIENT'S RESPONSE

11.CONCLUSION

Needs

Action planned

Actions taken

Questionnaire completed by:

Name of interpreter:

Date completed

University of Cape Town

9. APPENDIX 2:

STUDENT QUESTIONNAIRE

Thank you for participating in this study.

	No.....	Yes
1. Did you enjoy participating?	1 2 3 4 5	
2. Was it stressful?	1 2 3 4 5	
3. Did you find it difficult to talk To the patients?	1 2 3 4 5	
4. Did you empathise with them?	1 2 3 4 5	
5. Did you feel disconnected from them?	1 2 3 4 5	
6. Did you come away feeling upset?	1 2 3 4 5	
7. Will you do this kind of research again?	1 2 3 4 5	

NAME:.....

QUALIFICATIONS:.....

CURRENT STUDIES:.....

STUDENT INTERVIEWS

INTERVIEW WITH CAREY-ANN MOOLCRAFT

On 24 May 2005, I interviewed Carey to get her views on this research project and to establish what effect this experience has had on her life.

She was involved with this research project for 5 months on a weekly basis.

According to her she felt disconnected with the patients, because of their different social backgrounds. Although she enjoyed completing the questionnaires, she became upset especially when there were children involved. She felt helpless, because she cannot solve the patients' financial problems for them and she could not take their guilt feelings away.

During and after the project, she felt **lucky, guilty and sad**. She realizes that she had grown a lot emotionally.

She did not experience difficulty in keeping a distance. She sees her involvement with the project as an awakening life experience.

As a result of her involvement with this project, she is doing the Hospice Caregivers Course at the moment.

INTERVIEW WITH VALERIE CLARKE

On 24 May 2005, I interviewed Valerie to find out the effect this research project has had on her life.

She was involved with this project for 5 months on a weekly basis.

According to her, she enjoyed talking to the patients. It broadened her view on life and her perceptions of the patients. She finds she has benefited a lot by taking part in this project, i.e. self-growth, academically and it was different from the things she normally does. She also became in touch with reality.

At no stage she felt to withdraw from the project. She felt privileged to be part of it. For her it was a good life experience.

Because of her involvement with this project, she is at the moment doing the Hospice Caregivers Course.

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CORRECTIONS:

The corrections have been done in response to the outline given. Page numbers in brackets indicate where they have been inserted.

1. The questionnaire used on the rheumatoid patients was also used in a population of hospital patients, primarily xhosa speaking unemployed and living locally. The population investigated was very similar to the AIDS patients. The major difference was that they were older. (Page 15)
2. The questionnaire was largely one word answers. The description of the research has been appended (page 28). The patients are terminal and the use of a longer questionnaire did not seem appropriate (page 28). In addition this was a clinical study and not a research tool. (page 31).
3. The previously mentioned rheumatology questionnaire was in english with interpretation by the nursing staff. All treatment and management in the hospital is done using this medium of communication. The consent form in the pilot study was translated into xhosa but the nurses used the English translation of this when asking the patients to participate. The implementation would still require communication in English. (page 29)
4. A pilot study was done in 2004. (pages 15, 16 and 23)
5. The patients were not told that they were considered terminally ill.. Unpredictability of Death in AIDS has been noted (page 20), In the experience of the staff that were considered highly likely to die (page 24) and they were surrounded by people were were dying every day with the same disease. The patient's perception of whether they were terminally ill might influence psycho-spiritual replies but would be unlikely to change

te perception of whether they had specific symptoms or a disability grant.

6. Bias due to socially acceptable results: there was no difference between the information given by the patients and the observations of the nursing staff. (page 30).

7. The impact on ward routine by the use of nursing staff as translators.

The nursing staff chose the timing of the interviews. And helped in the selection of patients. The nursing staff have been deeply concerned by the impact of so many people dying in the ward. They were therefore happy to be involved in any process which would help to relieve the distress of the patients. (Introduction and page 32).

8. The selection of patients was based on the times given to the researchers by the nursing staff (page 32). The selected patients reflected the demographics of the ward patients in that they are all hospital patients, the majority are xhosa speaking and 30 to 50% of the patients have AIDS. (page 32).

PRESENTATION OF THE RESULTS:

1. The results have been separated from the discussion by introducing a new chapter Discussion of the results (page 43).

2. No attempt to discuss the results statistically: This is a descriptive clinical study mainly designed to demonstrate the range and variety of the symptoms that are not addressed in AIDS patients and that it is appropriate to address these and that the outcome is improved. The frequency and incidence of specific symptoms have been well covered by researchers such as Badri and Norval (references page 55 and 56).

3. Table 1 amended to read renal failure and skin infection with septicaemia.
4. Figure 2 description has been amended to read that this shows the total numbers of Patients in the first column and the number of these who received palliative care in the second column. (page 14).
5. Vertical axis in figure 3 has been corrected to read numbers (page 17).
6. Table 2 has been corrected to read skin infection and visual impairment (page 40)
7. The numbers and percentages have been corrected (page 46).
8. The meaning of the results has been reviewed (page 46-47).
9. The conclusion have been amended. Previous work has shown an increased duration of life (page 14). In this study the patients were highly likely to die on past experience. The fact that they did not is possibly related to the care they received (page 49 and 50)